



McMillan, T. (2013) Outcome of rehabilitation for neurobehavioural disorders. *NeuroRehabilitation*, 32 (4). pp. 791-801. ISSN 1053-8135

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Deposited on: 09 August 2013

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Outcome of rehabilitation for neurobehavioural disorders

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Abstract.

BACKGROUND: The evidence base on neurobehavioural disorders and their rehabilitation has been growing for four decades. Over that time understanding of the need for effective interventions for a range of handicaps in personal, interpersonal and employment spheres has developed. There is a continuing need to demonstrate whether interventions, are effective and cost-sensitive. Moreover, in pursuing effectiveness, clinicians need to be able to predict which individuals are likely to benefit from a programme and here, clinical experience needs to be informed by research evidence.

OBJECTIVE: To review the outcome of rehabilitation for neurobehavioural disorders.

METHODS: This review initially considers the background to neurobehavioural rehabilitation and discusses methodological issues. It reviews the evidence for neurobehavioural interventions for severe head injury with emphasis on holistic models of care, behavioural treatments, interventions in non-specialist settings and for emotion perception and self-awareness.

RESULTS: In general, there is a need for further high quality studies with longer follow-ups and evidence for generalisation in the community. However, there is a growing consensus that intensive holistic rehabilitation programmes can improve community reintegration and self-efficacy. For behaviour disturbance the evidence base largely comprises studies with weaker (single group or single case) designs. Overall studies here provide limited evidence in support of behavioural approaches for externalised behaviour such as aggression. Further RCT or group comparison studies are needed. In terms of negative behaviours such as apathy, there are few studies on head injury and conclusions cannot be made with confidence. Self awareness is a key issue associated with good outcome in general and research to date supports use of interventions that focus in on-task behaviour and education. The correct perception of emotions in others is a precursor to successful social interaction, and here there is very little evidence although early studies are encouraging.

CONCLUSION: There is mounting evidence to support the effectiveness of non-pharmacological interventions for neurobehavioural disorders. Successful outcomes are often associated with intensive and prolonged interventions involving multidisciplinary working.

Keywords: Neurorehabilitation, neurobehavioural, holistic rehabilitation, traumatic brain injury

1. Introduction

Neurobehavioural rehabilitation is an approach that developed from behavioural psychology in the 1970's (Wood & Eames, 1981) and later developed to include aspects of cognitive psychology and to further emphasise social outcome (Wood, 2001). It focuses on disability outcome rather than impairment after brain

injury and drives towards social integration, when possible in the community. Hence physical and social environments are keys to change and maintenance of behaviour. More specifically its purpose is to reduce antisocial behaviour, to reduce apathy and indifference, to reduce the effects of executive dysfunction on independent care functions and to facilitate pro-social behaviour. The clinical features of neurobehavioural

disorders can present as negative behaviours including apathy, poor initiation and social withdrawal or as positive behaviours, which for example are associated with disinhibition, impulsivity or emotional dyscontrol. The interplay between perception, executive function, emotional control and physical skills is understandably complex and made more so by the impact of social responses and environment on present and future behaviour. Hence late after injury, it is not uncommon for relatives to report improvement, which on further investigation can be explained by development of an understanding of relationships between environment and behaviour with consequent adjustments of the environment and responses to behaviour that reduce the likelihood of antisocial behaviour. The earlier work of Kurt Goldstein emphasised the need to structure the patient's environment to cope with daily demands, given the persistence of cognitive and emotional effects of the brain injury and the need for a compensatory (rather than restorative) approach to neurorehabilitation. In this way the person learns to adjust to a restricted environment and to accommodate this in their sense of self. Hence neurorehabilitation can only be successful when the patient has some understanding of their problems and some willingness to participate in interventions (Goldstein, 1952). Adjustment to an impaired or threatened sense of self or identity is associated with a change in roles that can often accompany a severe head injury, including roles and status in the family, with friends, in terms of career and employment and in financial prospects.

In general terms, over the past 30 years there has been an exponential growth in publications on rehabilitation for brain injury, with around 261 in 1980's, 922 in the 1990's and 1,980 in the 2000's. This trend is set to continue with over 450 publications in less than 2 years in the present decade. There are several systematic reviews of neurorehabilitation outcome and effectiveness including of multidisciplinary rehabilitation and of more specific interventions for specific problems (Chesnut et al., 1999; Cattalani et al., 2010; Turner-Stokes et al., 2011; Ylvisaker et al., 2007; Cicerone et al., 2005, 2011).

This review focuses on the evidence for interventions that encompass the neurobehavioural approach such as holistic rehabilitation. It includes neurorehabilitation in non-specialist environments and key elements of the approach including treatments for challenging behaviour and apathy and for deficits in self-awareness. It will not review specific interventions for cognitive impairment or more general interventions for inpatient

rehabilitation (see Turner-Stokes et al., 2005; Cattalani et al., 2010; Cicerone et al., 2011). First however some methodological issues are discussed.

2. Some methodological and conceptual issues

Evaluation of outcome after head injury is bedevilled by methodological issues. This in part reflects the head injury population which is heterogeneous in terms of demographics and outcomes (Whitnall et al., 2005). In outcome research, natural recovery from the injury and psychological adjustment to its effects need to be considered and also of relevance is what is 'brought to the injury' in terms of preinjury medical and social history. The complex interplay between these factors is associated with a wide range of outcomes, and difficulty predicting outcome. For example, severity of injury alone is not a precise indicator of outcome, especially late after injury (McMillan et al., 2012; see also Ponsford, 2013). Corrigan et al. (2003) discuss a number of issues that have led the literature on outcome at times to be inconsistent. These include use of samples that do not represent the population (eg hospitalised, military, inpatient rehabilitation), excluding participants with a history of substance misuse, significant loss to follow-up or drop out from interventions and non-random loss to follow-up (eg by those who are socially deprived or were victims of violence). These biases in sampling and follow-up could lead to over-positive outcome reporting and there is a need for studies to present data comparing those who are followed-up and those who are not.

In terms of outcome following intervention studies, the gold standard is the randomised control treatment (RCT) design with double blind, but this is essentially impossible in neurorehabilitation. The RCT paradigm replicates as far as possible the rigour of a laboratory experiment, minimising human bias on assignment to group, intervention and assessment of effect. The number of RCTs on rehabilitation of head injury (with single blind) has risen successively in each of the past three decades (Lu et al., 2012); although these numbers remain very small relative to the total number of studies on head injury published. Although the RCT design can work well in drug treatment studies, in neurorehabilitation studies it is often impractical. Concealment of the intervention under investigation from the therapist(s) who delivers the intervention is difficult. It can be difficult to conceal group identity from the participant, who needs to be informed about the

nature of the study and their involvement in order to provide consent to take part, and a control treatment may have limited 'face' validity. It is possible for the assessor to be blind to the intervention group and this should be a requirement in principle including non-RCT trials. In practice though, there is always a danger that the brain injured patient will inadvertently provide information during assessment that will reveal their group membership to the assessor. Maintaining discrete integrity between target and control interventions is also difficult to achieve. Within a service there is likely to be cross-talk within the multidisciplinary team who may vary their routine practice as a result (given that their primary focus is to help their patients). This can be of particular relevance where the control condition is treatment as usual in the same unit, and may involve elements of the target intervention that can be modified or added to in the controls. An option might be to randomise units to treatment or control conditions. However, this assumes parity across units in terms of non-target aspects of the intervention including admission criteria, the general rehabilitation process (including its structure, content and intensity), the patient group (including local demography), staff training, the staff/patient ratio and the experience of staff in working with brain injury, the neurorehabilitation environment and the discharge process. There is also an issue of needing to tailor aspects of neurorehabilitation to the individual (given the heterogeneity in presentation including comorbidities) which can introduce imbalances between groups (eg in intensity of input). Assignment to neurorehabilitation versus wait list control can be problematic because of the issue of natural recovery, that admission from a wait list for neurobehavioural rehabilitation often reflects clinical need rather than waiting time and existing evidence that earlier rehabilitation is more effective. These factors can raise ethical concerns if allocated to 'waiting list' or intervention on a random basis. Finally, some argue that there are human factors associated with taking part in an RCT that can affect outcome (Kaptchuk, 2001). These include an 'unknown' heightening of vigilance in the participant or therapist to signs of group membership and then a reaction (eg a positive or negative expectation of benefit) according to that belief (which is particularly relevant in neurorehabilitation given that group identity may be relatively obvious to the participant). For useful discussion of 'the control group dilemma', see Hart et al. (2008).

Not only are good quality RCTs very difficult to deliver, but the perception of health purchasers can be

that their absence equates to evidence for the ineffectiveness of neurobehavioural interventions. This is a criticism that has been levied more generally against evidence based medicine and the difficult interface between politics and science (Saarni & Gylling, 2004). As Whyte (2002) points out, the weight of evidence from observational studies can be persuasive, providing that methodological limitations differ between studies. Indeed there is some support for this from studies in general medicine (Concato et al., 2000). There is a need to accept that even if standard in other areas, the RCT cannot be the general standard for acceptable studies in neurorehabilitation, and a balance needs to be struck where due weight is placed on rigorous studies which have adequate controls and which avoid obvious sources of bias- such as those found in uncontrolled studies driven by clinical units, who are understandably motivated to publish positive outcomes from their work. In achieving a balance there is also a need to reaffirm a role for good quality single case research.

The value of single case research in the history of neuropsychology is undeniable (Benton, 2000; Code et al., 1996; Mateer, 2009; Morgan et al., 2011). In recent years however some journals have moved away from publishing *N of one* designs. Certainly the value of single case designs is limited because of potential observer bias, because findings may not generalise from one individual case to another, because of difficulties in providing adequate controls and valid statistics, and in establishing effect size (Tate et al., 2008). From a clinician's perspective, there are arguments against sole reliance on group-comparison studies where an intervention procedure that is found to improve outcome between groups, can seem difficult to apply to specific individuals. Indeed the difficulty in drawing conclusions from group based research has been raised in systematic reviews on neurorehabilitation for brain injury (Turner-Stokes et al., 2011). Finally there is a general issue of publication bias, where intervention studies showing no effects are found less often in the literature than those showing an effect. This has been recognised for some time and has been termed the 'file-drawer' effect whereby 5% of published studies may be guilty of Type 1 error, and 95% of studies which have non-significant effects are unpublished (Rosenthal, 1979, Scargle, 2000). The implication of this bias in submissions and in publishing positive treatment outcomes significantly weakens the value of systematic reviews and meta-analyses and is bound to be at great cost to understanding and developing effective treatments.

3. Do neurobehavioural interventions improve outcome for people with acquired brain injury?

3.1. Holistic approaches

Yehuda Ben-Yishay's concept of a therapeutic community drew on Goldstein's view of neurorehabilitation as encompassing a restoration of identity that has been affected by brain injury. Ben-Yishay's work developed in New York in the mid-1970's, using the principle of a therapeutic milieu, whereby the patient is encouraged to participate by staff, relatives and brain injured peers. The programme would systematically help the patient to understand their difficulties, how impairments interact and their impact on function. A process of adjustment would then allow the patient to learn and incorporate compensatory strategies into daily living and to become able to self-manage, with this facilitated by the involvement of relatives. The programme would then move on to work with impulsive and poorly planned behaviour and difficulties in initiating or sustaining behaviour. Included in the process was individual and family counselling (Ben-Yishay, 1996). The approach was further developed by Prigatano with emphasis on psychotherapy. Both of these programmes were intensive, for example Prigatano's averaging 6 hours a day, 5 days a week for 6 months (750 hours). Prigatano et al. (1984) reported on 18 treated and 17 untreated people with head injury and found in the treated group greater (but modest) improvement in neuropsychological functioning, a substantial decrease in emotional distress and that more returned to work. They noted that patients who had problems with awareness and who could be helped to accept that they had deficits were the best candidates for the programme.

Fundamental to the holistic approach is multidisciplinary working with the individual as an entity rather than working on single areas of difficulty, and the incorporation of a compensatory approach to problems rather than a restorative approach (Ben Yishay, 1996). Key is the development of insight, adjustment and adaptive skills, the use of psychotherapy and the involvement of the family in rehabilitation facilitate the focus on generalisation from the rehabilitation environment to the community.

Systematic reviews of the effectiveness of holistic rehabilitation conclude that there is sufficient evidence to recommend these post-acute programmes for severe brain injury, with gains in functional independence, community integration and productivity,

including interventions late after injury (Cicerone et al., 2005; Cattalani et al., 2008; Cicerone et al., 2011). These reviews emphasise a need for treatments that are intense and have a relatively long duration. In support of this are five Class II (non-randomised design with control group) studies and thirteen Class III studies (single group studies). There are three Class I studies (RCTs): Cicerone et al. (2008) compared holistic rehabilitation with standard neurorehabilitation. The holistic rehabilitation (15 hours a week for 16 weeks) was structured around themes similar to the phases employed by Ben Yishay, and gains in community integration, and self-efficacy for symptom management were found and maintained at 6 month follow-up. Salazar et al. (2000) found no evidence to support an intensive inpatient rehabilitation programme with several holistic rehabilitation components, rather than a home care package involving education and counselling. This latter study has been criticised on a number of grounds including that some of the 120 participants may have had injuries of a severity that did not warrant an intensive approach and that the participants were acutely injured and comprised military personnel (Prigatano, 2003; Cicerone et al., 2008). A third RCT (Vanderploeg et al., 2008) compared cognitive-didactic and functional-experiential approaches, again in military personnel. The cognitive-didactic approach emphasised explicit learning including encouragement of errors and also the development of awareness of deficits (which is key to the holistic approach). The functional-experiential approach emphasised motor and implicit learning using errorless learning and with no emphasis on self-awareness. Hence two 'active' rehabilitation interventions of similar intensity were compared. The sample sizes of around 180 per group were relatively large, and the intervention encompassed around 100–250 hours over 20–60 days. Superiority in the cognitive-didactic group was reported post-treatment in terms of cognitive function. No difference in employment outcome is reported at 1 year follow-up.

3.2. Behavioural interventions

Treatments are usually individually tailored and based on classical and operant conditioning principles derived from learning theory and target one or a few behaviours using contingent reinforcement as a vehicle for change. Although some might target disruptive behaviour soon after injury for treatment, for many patients this is a temporary phase during recovery which resolves naturally as post traumatic confusion ends.

Arguably the pressing issue early after injury is most often one of safe management. These techniques can include orientation strategies prior to and during self-care interventions, avoidance of triggers for behaviour, environmental controls and distraction at the onset of behaviour. They can reduce the frequency of disruptive behaviour during the early phase of recovery, but with an expectation that the behaviour will re-emerge if the management techniques are withdrawn and confusion remains. There are some exceptions to this. For example, where there is a physical cause for agitation in the early days after injury or when the patient is not aware of, or is unable to communicate causes of discomfort, such as drug or alcohol withdrawal, constipation, urinary retention or pain.

For challenging behaviour that persists beyond the early recovery phase, there is a strong argument for effective intervention given the high care costs required for safe management and the very negative impact on quality of life for the patient and their family (Winkler et al., 2006). Here there is a greater weight of research evidence, most of which is on positive, disruptive anti-social behaviour. Ylvisaker et al. (2007) reviewed 65 studies comprising a total of 172 children and adults with brain injury (154 with head injury and 67% were adults) and behavioural disorders. It is of note that single case designs were included. In fact most studies were single case designs, with only four group studies (two RCT and two single group, pre- versus post-intervention studies). In most cases aggression, violence and/or impulsiveness were key problems. They group behavioural approaches into contingency management procedures, positive behaviour interventions and combinations of these two approaches. Contingency management procedures involve alteration of behaviour by manipulating its consequences (for example with verbal praise, token economies or time out from reinforcement) and are generally associated with applied behaviour analysis. Positive behaviour interventions are generally associated with antecedent-focussed procedures. Most studies report improvements in externalised behaviour, some maintenance of treatment gains at follow-up and social validity of the treatment in some sense (ranging from increased engagement in rehabilitation to return to work). Only a minority of studies report any information on generalisation of treatment gains to non-treatment settings, and of these 21/27 reported some positive transfer of gains. Ylvisaker et al. highlight a number of significant methodological problems including small sample sizes, inadequate controls (only two RCTs with a combined total $n = 24$), failure

to report generalisation and maintenance of treatment gains, references to unpublished studies with no treatment effects, potential subject selection bias and note that studies on other diagnostic groups consistently find these treatments to be ineffective. Overall however, Ylvisaker et al. conclude that both procedures can be viewed as 'evidence based treatment options' with a 'moderate' degree of clinical certainty. This view is largely based on a strong consensus from single case studies with effective control. They equate the evidence overall, as support at the level of a '*practice guideline*'. They quote categories of effectiveness from Miller et al. (1999), these are; *practice standards* (high degree of certainty based on Class I or very strong Class II evidence); *practice guideline* (moderate certainty based on Class II or strong consensus from Class III evidence) or a *practice option* (inconclusive evidence-or where there is conflicting evidence).

More recently, Cattelani et al. (2010) systematically reviewed studies on adults, and included single cases with adequate control. They report 63 studies with a total of around 1100 patients with neurobehavioural and psychosocial problems after brain injury, including some studies involving holistic rehabilitation and some on cognitive behaviour therapy. Most studies describe patients with predominantly externalised symptoms. They report that most of the 33 studies (combined total $n = 151$) on challenging behaviour used contingency management and or positive behaviour interventions and demonstrate improvements in target behaviours. Positive outcomes were found in single case design studies and not in two small RCT studies (total $n = 23$). In studies using CBT for internalisation of self-regulation strategies (total $n = 201$), there was no or equivocal evidence for benefit in 4 Class I or II studies, a positive change in behaviour in 3 Class III studies and no or mixed effects in 6 Class III studies. They give less weight to the single case studies, and given the absence of support from Class I and Class II studies, view the evidence at the level of *practice options*, a weaker outcome than that of Ylvisaker et al. (2007). They urge further studies with stronger methods.

In terms of negative behaviours, the greater likelihood of patients with low motivation or drive to benefit from neurobehavioural interventions has been acknowledged for some time (Eames & Wood, 1985), and there have been relatively few studies evaluating interventions. A systematic review of RCTs for apathy found only one which did not involve a neurobehavioural treatment (cranial stimulation) and did not show clear evidence for effectiveness (Lane-Brown

& Tate, 2009a). A review of a broader range of designs included cerebrovascular accident, encephalitis and dementia in addition to head injury and found 28 non-pharmacological intervention studies (Lane-Brown & Tate, 2009b). The majority of studies were on dementia (21/28). Five on head injury included the RCT on cranial stimulation; one group comparison study reported improvement in goal directed behaviour following a problem solving intervention (Von Cramon et al., 1990) and three single N design studies reported improvements in a total of 4/6 mild head injuries using computerised training or external cueing strategies. Since then a further single case study by Lane-Brown and Tate (2010) reported improvement in initiation and goal directed activity following motivational interviewing and external compensation over a 7 month period. Overall evidence is limited and further work is needed before conclusions regarding treatment efficacy can be made with confidence.

3.3. Neurobehavioural interventions in non-specialist settings

Given the high expense of treatment in a specialist neurobehavioural unit and the potentially limited availability of such a service, the issue of carrying out neurobehavioural interventions in non-specialist settings has often been raised.

There has also been an attempt to reduce problems with generalisation of learning in neurorehabilitation units to the community, by providing rehabilitation in the person's home. In part this reflects more general political and health service trends towards care in the community. In the Cochrane systematic review by Turner-Stokes et al., two RCTs on head injury that compare community/home based rehabilitation with hospital outpatient or 'treatment as usual' are reviewed. It was concluded that there is 'limited evidence' for improvement in disability. Although there are now some additional relevant studies this conclusion remains valid. Included is a single blind RCT by Powell et al. (2002) on head injury that compared around 40 hours community neurorehabilitation by an outreach team over a 6 month period, to brief provision of community neurorehabilitation followed by information only. They report improvements in activities of daily living and subjective well being in the community neurorehabilitation group, but no differences in employment or social interaction. Second, Bowen et al. (2001) used an RCT design to study carers of head injury people, comparing groups provided with community outreach or treatment

as usual. Six months post-injury, carers reported no significant differences in distress or information received about brain injury. Almost a third of participants did not receive the intervention they were assigned to. The authors note that the study was underpowered. Given the preliminary nature of the study, the arbitrary setting of p at <0.01 , (to avoid Type 1 error) may be overly strict. There are two more recent RCTs involving carers. Rivera et al. (2008) compared problem solving training or education using an RCT design in carers of head injured people at home. Carers with problem solving training reported decreases in depression, health complaints and dysfunctional problem solving styles over the 12 month intervention period (12 sessions; 4 in home and 8 by telephone). Carnevale et al. (2002), considered change in the burden of three group of carers of people with head injury following community based education and behaviour management training, or education or no treatment using an RCT design. The initial levels of care burden and distress predicted these factors 14 weeks after study onset and no group effect was found. The sample size was modest (8–10 per group), and the study was probably underpowered.

In terms of Class II group comparison studies, Willer et al. (1999) compared two acquired brain injury groups who received either 'traditional' home based or intensive residential neurorehabilitation in the community. The groups were matched for demographics, injury severity and time since injury. Interventions in the home based (control) group were highly variable, with a third receiving no formal input; the home-based group had better motor function and were more emotionally disabled initially and post-treatment. Almost all participants had previously received hospital-based inpatient neurorehabilitation. Overall, greater improvements in motor and cognitive function are reported in the residential-community neurorehabilitation group. This study demonstrates several of the difficulties in carrying out research of this kind. It gives some weight to the view that intensive residential neurorehabilitation is superior to the more haphazard 'traditional' community intervention that is still widely found. Cusick et al. (2003) compared outcome of community based neurorehabilitation to no service in head injured people who had previously had inpatient neurorehabilitation ($n = 66$ per group). Findings were mixed, with outcome in the community group superior on 4 variables and superior in the controls on 8; there were 78 variables considered, and clearly a risk of type 1 error. The authors point to a number of additional design limitations. Ponsford et al. (2006), compared

outcomes 2 years post-injury following a change in service provision from hospital-outpatient based to community based neurorehabilitation (all patients had already received inpatient neurorehabilitation). Patients received around 100 hours of therapy. Differences in ADL or employment were not found. Those given community neurorehabilitation received fewer one-one sessions, reported more communication problems, reported a need for greater social support and were more likely to be dependent for shopping and financial management tasks. Smith et al. (2006) compared community neurorehabilitation to hospital outpatient neurorehabilitation in terms of family function and carer health. The design was retrospective and compared groups at a single outcome point. More positive outcomes in the community neurorehabilitation group were found in terms of family function and need, carer health and carer emotional acceptance.

Doig et al. (2010) systematically review outcomes after day hospital or home based neurorehabilitation in a further 15 studies on stroke patients, and conclude that home based neurorehabilitation is 'not inferior'. McCabe et al. (2007) review in addition, several single group studies on ABI and conclude that no clear benefit of community over hospital based neurorehabilitation is established. Cullen et al. (2007) conclude that the evidence for benefit of community neurorehabilitation for ABI is limited.

Overall there does not seem to be evidence to strongly contraindicate rehabilitation in the home but there is limited evidence for effectiveness. There is a need to consider the comparability of control groups in terms of intensity and duration of input and in what circumstances home based rehabilitation might have benefits over day-care or inpatient rehabilitation.

In terms of non-specialist ward based interventions, the need for interventions can arise on an intermittent basis, and evidence is mainly to be found from case studies. There is limited evidence from single case design research that tailor made interventions can be effective including in unusual and disruptive cases (Johnston et al., 1991) when key factors including the environment and training and supervision of staff are covered (see Wood & Alderman, 2011).

4. Identity, emotional perception and self-awareness

An individual's concept of self and identity has been recognised to be of fundamental importance since the

early writings in psychology (James, 1880). It is based on our knowledge and experience of past and present events and is linked to our expectations of the future. Following a severe head injury knowledge and experience of our past becomes incomplete. There is a period of time during which there is little or no memory for events or the influence of the individual on them. This gives rise to curiosity and concern, to an extent that can be misinterpreted as post traumatic stress (Sumpter & McMillan, 2006). This absence of experience and memory of events for the injury is also linked to limitations in awareness and belief in changes in the 'self' after a head injury in addition to limitations resulting from the brain injury itself. Goldstein perceived restoration of impaired identity of self, using compensatory strategies and adjustment, which are core features of holistic neurorehabilitation programmes, as key to successful rehabilitation. Recently there has been a renewed interest in relationships between brain injury, self, identity and adjustment (Gracey & Ownsworth, 2008).

Self-awareness is associated with better rehabilitation outcome (Scherer et al., 1998; Ownsworth et al., 2006). It is common for people with brain injury to have a limited understanding of their own capacities, believing their abilities to be much as before the brain injury. In addition they may have more fundamental impairments in the ability to interpret the behaviour of others. Included here are impairments in perception of facial expressions, vocal intonation and in comprehending intent. These difficulties may also be compounded by more general cognitive impairments in attention, information processing and memory (Milders et al., 2003; de Sousa et al., 2011). Difficulties at a metacognitive level include self-reflection and conceptualising relationships between self and others. The head injured person may seem cold and unempathic to others (Wood & Williams, 2008; O'Neill & McMillan, 2012). Overall someone with a severe head injury can have a limited understanding of the negative impact of their behaviour on others. Hence, they may persist in socially inappropriate or risky behaviour and not learn from their experiences. These factors are associated with common findings in the long term such as social isolation, work failure and long term unemployment (Wood & McMillan, 2001).

Research on change in self-awareness over time is complicated by adjustments by the family and in the environment that may deaden the impact or reduce the likelihood of negative social events but without reducing the deficit in awareness. Rehabilitation has made use of feedback on task performance to challenge

unrealistic beliefs. Klonoff et al. (1989) observed behaviour during cognitive retraining tasks and used videotape to challenge patient's beliefs about their abilities. Psychotherapeutic approaches emphasise the establishment of the therapeutic alliance, through which the patient is helped to make reasonable choices and to learn how their defence system leads to poor choices (Prigatano, 1989; 2005).

Crosson's Pyramid model of self-awareness encompasses three hierarchical levels; intellectual (awareness of an impairment that might affect daily life), emergent (aware of the problem when it is actually happening) and anticipatory awareness (able to anticipate a difficulty associated with a problem). Toglia and Kirk (2000) developed Crosson's (1989) model, to incorporate metacognition in their Dynamic Comprehensive Model of Awareness. This model includes knowledge about, and belief in, oneself and understanding of the demands and contexts of tasks. It adds ongoing monitoring and regulation of task-orientated behaviour. These models have been used to develop rehabilitation interventions, although there is currently limited evidence for effectiveness. Goverover et al., (2007) adopted Toglia and Kirk's multidimensional model of awareness and used a single blind RCT design to compare an awareness training protocol within a more general rehabilitation intervention to the more general intervention alone. Pre-group allocation assessment was compared to outcome a day after six, 45 minute sessions of treatment. Participants ($n = 10$ per group) were living in the community, on average a year post head injury. They report improvement in awareness and self-regulation of cognitive aspects of task performance (but not of more general function) in the target group and interpret this as improvement in ability to recognise and self correct errors. In an RCT on head injury, Cheng et al. (2006) report greater improvements in cognitive aspects of daily living task performance and greater self-awareness, but not more general improvements in daily function. An RCT by Medd and Tate (2000) used a cognitive-behavioural paradigm (6 sessions over 5–8 weeks; $n = 8$) to treat anger in people with acquired brain injury. The treatment included training in self-awareness, and improvement in outward expression of anger was found, compared to wait list controls. In terms of single group studies, Ownsworth et al., (2000, 2004) report pre/post intervention changes in self-awareness in people with ABI who underwent a 16 week community based group rehabilitation programme involving education about brain injury, feedback on task performance, guided self-reflection,

role play, problem solving, learning compensatory behaviours and practice of new behaviours. They report improvement in emergent and anticipatory awareness and use of strategies with maintenance of gains in self-awareness and self-regulation at 6 month follow-up. Malec and Moesner (2000) report improved self awareness in people with ABI after a holistic day programme; improved self awareness was associated with independent living but not employment. Others also report improvement in self-awareness as a result of education and feedback using a single group pre and post intervention design with $n = 17$ (Roberts et al., 2006). A number of single case design studies support the use of metacognitive training to improve self awareness and 'on – task' performance (Toglia et al., 2010). Cicerone et al. (2011) recommend metacognitive training in people with deficits in self-awareness at the level of a *practice standard* (high degree of certainty).

A further and fundamental factor governing skilled interaction in a social setting is perception of emotion in others. Several studies point to impaired ability to perceive facial expressions in some after a head injury (Babbage et al., 2011). Bornhofen and McDonald (2008a) argue that the limited effectiveness of behaviourally orientated social skills programmes for people with head injury may reflect a need to improve basic emotional perception. Bornhofen and McDonald (2008a) report an RCT involving 25 hours of training with errorless learning or self-instruction compared to wait list controls ($n = 6$ per group) and report outcome 1 and 6 months after treatment. Despite the small sample sizes, modest improvements in perception of facial expressions and ability to make social inferences are reported in treated groups, with greater effect in self-instruction group. There was wide variability within groups, and possibly better outcomes in those with less cognitive impairment overall. In an earlier study, Bornhofen and McDonald (2008b) report improvements in perception of facial expression and voice tone after 8 weeks of a programme that included both errorless learning and self-instruction training in an RCT comparing intervention and wait list controls ($n = 5$ per group). Clearly these studies are of interest and beg replication with larger sample sizes.

5. Conclusions

The evidence to support interventions for neurobehavioural disorders continues to grow (eg compare Cicerone et al., 2008 and 2011). What is needed now

is the further development of theory linked interventions with good quality designs. Future studies need to take into account key limitations that have been noted in several reviews, including avoidance of bias, use of representative samples, definition of sub-groups likely to benefit, the need for adequate controls, adequate statistical power, adequate intensity and duration of intervention and longer post-treatment follow-up. There needs to be a focus on outcomes that include quality of life, social participation and daily function. In more general terms studies of good quality with negative findings need to be submitted and pursued into publication. The role of single N design and small scale studies could be clarified, in terms of their value in developing proof of concept and as published precursors that inform larger scale studies that develop from them. The use of proof of concept studies is relatively widespread in other areas including pharmacotherapy and of more relevance, psychosocial interventions in mental health and should be used more formally in neurorehabilitation.

What we can say now is that there is evidence to support the use of intensive holistic rehabilitation for head injury. Behavioural interventions can be effective although the evidence base needs to be developed further. Neurobehavioural rehabilitation can be effective in the home, although the relative effectiveness and cost-effectiveness compared to intensive inpatient or day care rehabilitation is unclear. There is evidence to support the use of interventions for impaired self-awareness, and further work linking this to theoretical models is needed. Given the sizeable minority of people with head injury who demonstrate impaired emotion perception, early treatment studies are encouraging.

When the pioneers in this field began their journey they were faced with the 'fact' that neurogenesis does not occur, and this is consistent with the traditional compensatory approach in neurorehabilitation. Some two decades ago studies in humans indicated that this is not the case (see McMillan et al. 1991). This should lead us now towards greater optimism and new horizons in neurorehabilitation.

References

- Babbage, D. R., Yim, J., Zupan, B., Neumann, D., Tomita, M. R., & Willer, B. (2011). Meta-analysis of facial affect recognition difficulties after traumatic brain injury. *Neuropsychology*, 25(3), 277-285.
- Benton, A. (2000). *Exploring the history of neuropsychology*. Oxford University Press: Oxford.
- Ben-Yishay, Y., Silver, S., Pisetsky, E., & Rattock, J. (1987). Relationship between employability and vocational outcome after intensive holistic cognitive rehabilitation. *J Head Trauma Rehabilitation*, 2(1), 35-48.
- Ben-Yishay, Y. (1996). Reflections on the evolution of the therapeutic milieu concept. *Neuropsychological Rehabilitation*, 6, 327-343.
- Bowen, A., Tennant, A., Neumann, V., & Chamberlain, M. A. (2001). Neuropsychological rehabilitation of traumatic brain injury. Do carers benefit? *Brain Injury*, 15, 29-38.
- Bornhofen, C., & McDonald, S. (2008a). Comparing strategies for treating emotion perception deficits in traumatic brain injury. *J Head Trauma Rehabilitation*, 23(2), 103-115.
- Bornhofen, C., & McDonald, S. (2008b). Treating deficits in emotion perception following traumatic brain injury. *Neuropsychological Rehabilitation*, 18, 22-44.
- Carnevale, G. J., Anselmi, V., Busicho, K., & Millis, S. (2002). Changes in ratings of caregiver burden following a community based behaviour management programme for persons with traumatic brain injury. *J Head Trauma Rehabilitation*, 17(2), 83-95.
- Cattalani, R., Zettin, M., & Zoccolotti, P. (2010). Rehabilitation treatments for adults with behavioural and psychosocial disorders following acquired brain injury: A systematic review. *Neuropsychological Review*, 20, 52-85.
- Cheng, S. K., & Man, D. W. (2006). Management of self-awareness in persons with traumatic brain injury. *Brain Injury*, 20, 621-628.
- Chesnut, R. M., Carney, N., Maynard, H., Mann, N. C., Patterson, P., & Helfand, M. (1999). Summary report: Evidence for the effectiveness of rehabilitation for persons with traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 14(2), 176-188.
- Cicerone, K. D., Dahlberg, C., Malec, J. F., Langenbahn, D. M., Felicetti, T., Kneipp, S., et al. (2005). Evidence-based cognitive rehabilitation: Updated review of the literature from 1998 through 2002. *Archives of Physical Medicine & Rehabilitation*, 86(8), 1681-1692.
- Cicerone, K. D., Mott, T., Azulay, J., Sharlow-Gallela, M. A., Elmo, W. J., Paradise, S., & Friel, J. C. (2008). A randomized control trial of holistic neuropsychologic rehabilitation after traumatic brain injury. *Arch Phys Med Rehabilitation*, 89, 2239-2249.
- Cicerone, K. D., Langenbahn, D. M., Braden, C., Malec, J. F., Kalmar, K., Fraas, M., et al. (2011). Evidence-based cognitive rehabilitation: Updated review of the literature from 2003 through 2008. *Arch Phys Med Rehabilitation*, 92(4), 519-530.
- Code, C., Wallesch, C. -W., Joannette, Y., & Lecours, A. R. (1996). *Classic Cases in Neuropsychology*. Hove: Psychology Press.
- Concato, J., Shah, N., & Horowitz, R. I. (2000). Randomised controlled trials, observational studies and the hierarchy of research designs. *N Engl J Medicine*, 342, 1887-1892.
- Corrigan, J. D., Harrison-Felix, C., Bogner, J., Djikers, M., Terrill, M. S., & Whiteneck, G. (2003). Systematic bias in traumatic brain injury outcome studies because of loss to follow-up. *Archives Physical Medicine and Rehabilitation*, 84, 153-160.
- Crosson, B., Barco, P. P., Veloso, C. A., Bolesta, M. M., Cooper, P. V., Werts, D., et al. (1989). Awareness and compensation in postacute head injury rehabilitation. *J Head Trauma Rehabilitation*, 4, 46-54.
- Cullen, N., Chundamala, J., Bayley, M., & Jutai, J. (2007). The efficacy of acquired brain injury rehabilitation. *Brain Injury*, 21(2), 113-132.

- Cusick, C. P., Gerhart, A., Mellick, D., Breese, P., Towle, V., & White-neck, G. G. (2003). Evaluation of the home and community based services brain injury medicaid waiver programme in Colorado. *Brain Injury*, 17(11), 931-945.
- de Sousa, A., McDonald, S., Rushby, J., Li, S., Dimoska, A., & James, C. (2011). Understanding deficits in empathy after traumatic brain injury: The role of affective responsivity. *Cortex*, 47, 526-535.
- Eames, P., & Wood, R. L. L. (1985). Rehabilitation after severe brain injury: A follow-up study of a behaviour modification approach. *J Neurology, Neurosurgery, Psychiatry*, 48, 613-619.
- Doig, E., Fleming, J., Kuipers, P., & Cornwell, P. L. (2010). Comparison of rehabilitation outcomes in day hospital and home settings for people with acquired brain injury – a systematic review. *Disability and Rehabilitation*, 32(25), 2061-2077.
- Goldstein, K. (1952). The effect of brain damage on the personality. *Psychiatry*, 15(3), 245-260.
- Goldstein, K. (1959). Notes on the development of my concepts. *J Individual Psychology*, 15, 5-14.
- Goverover, Y., Johnston, M. V., Togli, J., & Deluca, J. (2007). Treatment to improve self-awareness in persons with acquired brain injury. *Brain Injury*, 21(9), 913-923.
- Gracey, F., & Ownsworth, T. (2008). The self and identity in rehabilitation. *Neuropsychological Rehabilitation (special issue)*, 18(5/6), Psychology Press, Hove.
- Hart, T., Fann, J. R., & Novack, T. A. (2008). The dilemma of the control condition in experienced based cognitive and behavioural treatment research. *Neuropsychological Rehabilitation*, 18, 1-21.
- Johnston, S., Burgess, J., McMillan, T. M., & Greenwood, R. (1991). Management of adipsia by a behavioural modification technique. *J Neurology, Neurosurgery and Psychiatry*, 54, 272-274.
- Kapchuk, T. J. (2001). The double blind randomized placebo-controlled trial: Gold standard or golden calf. *J Epidemiology*, 54, 541-549.
- Lane-Brown, A., & Tate, R. (2009a). *Interventions for apathy after traumatic brain injury*. London: Cochrane Collaboration, Wiley.
- Lane-Brown, A., & Tate, R. (2009b). Apathy after acquired brain impairment: A systematic review of non-pharmacological interventions. *Neuropsychological Rehabilitation*, 19(4), 481-516.
- Lane-Brown, A., & Tate, R. (2010). Evaluation of an intervention for apathy after traumatic brain injury: A multiple baseline single case experimental design. *J Head Trauma Rehabilitation*, 25, 459-469.
- Lu, J., Gary, K. W., Neimeier, J. P., & Ward, J. (2012). Randomised controlled trials in adult traumatic brain injury. *Brain Injury*, 26, 1523-1548.
- Malec, J. F., & Moessner, A. M. (2000). Self-awareness, distress and postacute rehabilitation outcome. *Rehabilitation Psychology*, 45, 277-241.
- Mateer, C. A. (2009). Neuropsychological interventions for memory impairment and the role of single-case design methodologies. *Journal of the International Neuropsychological Society*, 15(4), 623-628.
- McCabe, P., Lippert, C., Weiser, M., Hilditch, M., Hartridge, C., & Villamere, J. (2007). Community reintegration following acquired brain injury. *Brain Injury*, 21(2), 231-257.
- McMillan, T. M., Robertson, I. R., & Wilson, B. A. (1999). Neurogenesis after brain injury; implications for neurorehabilitation. *Neuropsychological Rehabilitation*, 9, 129-133.
- McMillan, T. M., Teasdale, G. M., Weir, C., & Stewart, E. (2012). Disability in young people and adults after head injury: 12-14 year follow-up of a prospective cohort study. *J Neurology, Neurosurgery, Psychiatry*. doi 10.1136/jnnp-2012-302746
- Medd, J., & Tate, R. L. (2000). Evaluation of an anger management therapy programme following ABI: A preliminary study. *Neuropsychological Rehabilitation*, 10, 185-201.
- Milders, M., Fuchs, S., & Crawford, J. R. (2003). Neuropsychological impairments and changes in emotional and social behaviour following severe traumatic brain injury. *Journal of Clinical and Experimental Neuropsychology*, 25, 157-172.
- Miller, R. G., Rosenberg, J. A., Gelinas, D. F., Mitsumoto, H., Newman, D., Sufit, R., et al. (1999). Practice parameter: The care of the patient with amyotrophic lateral sclerosis. *Neurology*, 32, 1311-1325.
- Morgan, J., Baron, I. S., & Ricker, J. H. (2011). *Casebook of Clinical Neuropsychology*. Oxford University Press.
- O'Neill, M., & McMillan, T. M. (2012). Can deficits in empathy after head injury be improved by compassionate imagery? *Neuropsychological Rehabilitation*, 22(6), 836-851.
- Ownsworth, T. L., McFarland, K., & Young, R. M. (2000). Self-awareness and psychological functioning following acquired brain injury. An evaluation of a group support programme. *Neuropsychological Rehabilitation*, 10, 465-484.
- Ownsworth, T. L., & McFarland, K. (2004). Investigation of psychological and neurological factors associated with clinical outcome following a group rehabilitation programme. *Neuropsychological Rehabilitation*, 14, 535-562.
- Ownsworth, T., & Clare, L. (2006). The association between awareness deficits and rehabilitation outcome following acquired brain injury. *Clinical Psychology Review*, 26(6), 783-795.
- Ponsford, J., Harrington, H., Olver, J., & Roper, M. (2006). *Neuropsychological Rehabilitation*, 16, 315-328.
- Ponsford, J. (2013). Factors contributing to outcome following traumatic brain injury. *Neurorehabilitation*. [this issue]
- Powell, J., Heslin, J., & Greenwood, R. (2002). Community based rehabilitation after severe traumatic brain injury. *J Neurology Neurosurgery, Psychiatry*, 72, 193-202.
- Prigatano, G. P. (1989). *Principles of Neuropsychological Rehabilitation*. New York: Oxford University Press.
- Prigatano, G. P. (2003). Challenging dogma in neuropsychology and related disciplines. *Archives of Clinical Neuropsychology*, 18(8), 811-825.
- Prigatano, G. P., Fordyce, D. J., Zeiner, H. K., Roueche, J. R., Pepping, M., & Case Wood, B. (1984). Neuropsychological Rehabilitation after closed head injury in young adults. *J Neurology Neurosurgery, Psychiatry*, 47, 505-513.
- Prigatano, G. P. (2005). Disturbance of self-awareness and rehabilitation of patients with traumatic brain injury. *J Head Trauma Rehabilitation*, 20, 19-29.
- Rivera, P. A., Elliott, T. R., Berry, J. W., & Grant, J. S. (2008). Problem-solving training for family caregivers of persons with traumatic brain injuries: A randomized controlled trial. *Arch Phys Med Rehabil*, 89(5), 931-941.
- Roberts, C. B., Rafal, R., & Coetzer, R. (2006). Feedback of brain imaging findings: Effect on impaired awareness and mood in acquired brain injury. *Brain Injury*, 20, 485-497.
- Rosenthal, R. (1979). The "file drawer problem" and tolerance for null results. *Psychological Bulletin*, 86, 638-641.
- Saarni, S. I., & Gylling, H. A. (2004). Evidence based medicine guidelines: A solution to rationing or politics disguised as science? *J Medical Ethics*, 30, 171-175.
- Salazar, A. M., Warden, D. L., Schwab, K., Spector, J., et al. (2000). Cognitive rehabilitation for traumatic brain injury. *Journal of the American Medical Association*, 283, 3075-3081.

- Scargle, J. D. (2000). Publication bias: The "file-drawer" problem in scientific inference. *Journal of Scientific Exploration*, 14(1), 91-106.
- Scherer, M., Bergloff, P., Levin, E., High, W. M., Oden, K. E., & Nick, T. G. (1998). Impaired awareness and employment outcome after traumatic brain injury. *J Head Trauma Rehabilitation*, 13, 52-61.
- Smith, M. J., Vaughn, F. L., Cox, L. J., McConville, H., Roberts, M., Stoddart, S., & Lew, A. R. (2006). The impact of community rehabilitation for acquired brain injury on carer burden an exploratory study. *J Head Trauma Rehabilitation*, 21, 76-81.
- Sumpter, R., & McMillan, T. M. (2006). Errors in self-report of PTSD symptoms after severe traumatic brain injury. *Brain Injury*, 20, 93-100.
- Tate, R. L., McDonald, S., Perdices, M., Togher, L., Schultz, R., & Savage, S. (2008). Rating the methodological quality of single-subject designs and n-of-1 trials: Introducing the Single-Case Experimental Design (SCED) Scale. *Neuropsychological Rehabilitation*, 18(4), 385-401.
- Toglia, J., & Kirk, U. (2000). Understanding awareness deficits following brain injury. *Neurorehabilitation*, 57-70.
- Toglia, J., Johnston, M. V., Goverover, Y., & Dain, B. (2010). A multicontext approach to promoting transfer of strategy use and self regulation after brain injury: An exploratory study. *Brain Injury*, 24(4), 664-677.
- Turner-Stokes, L., Disler, P. B., Nair, A., & Wade, D. T. (2005). Multi-disciplinary rehabilitation for acquired brain injury in adults of working age. *Cochrane Database of Systematic Reviews*, 3.
- Vanderploeg, R. D., Schwab, K., Walker, W. C., et al. (2008). Rehabilitation of traumatic brain injury in active duty military personnel and veterans. Defense and Veterans Brain Injury Center randomized controlled trial of two rehabilitation approaches. *Arch Phys Med Rehabilitation*, 89, 2227-2238.
- von Cramon, D. Y., Matthes-von Cramon, G., & Mai, N. (1991). Problem-solving deficits in brain injured patients: A therapeutic approach. *Neuropsychological Rehabilitation*, 1(1), 45-64.
- Whitnall, L., McMillan, T. M., Murray, G., & Teasdale, G. (2006). Disability in young people with head injury: A 5-7 year follow-up of a prospective cohort study. *J Neurology Neurosurgery, Psychiatry*, 77, 640-645.
- Willer, B., Button, J., & Rempel, R. (1999). Residential and home based rehabilitation of individuals with traumatic brain injury: A case controlled study. *Archives Physical Medicine Rehabilitation*, 80, 399-405.
- Winkler, D., Unsworth, C., & Sloan, S. (2006). Factors that lead to successful community integration following severe traumatic brain injury. *H Head Trauma Rehabilitation*, 21, 8-21.
- Whyte, J. (2002). Traumatic brain injury rehabilitation: Are there alternatives to randomised clinical trials? *Arch Phys Med Rehabilitation*, 83, 1320-1322.
- Wood, R. L. L. (2001). Understanding neurobehavioural disability. In R. L. L. Wood, & T. M. McMillan (eds.), *Neurobehavioural Disability and Social Handicap Following Traumatic Brain Injury* (pp. 3-28). Hove: Psychology Press.
- Wood, R. L. L., & Eames, P. G. (1981). Applications of behaviour modification in the rehabilitation of traumatically brain injured patients. In: G. Davey (ed), *Applications of Conditioning Theory*, London: Croom Helm.
- Wood, R. L. L., & Alderman, N. (2011). Applications of operant learning theory to the management of challenging behaviour after traumatic brain injury. *J Head Trauma Rehabilitation*, 26, 202-211.
- Wood, R. L. L., & McMillan, T. M. (2001). *Neurobehavioural Disability and Social Handicap Following Traumatic Brain Injury*. Hove: Psychology Press.
- Wood, R. L. L., & Williams, C. (2008). Inability to empathize following traumatic brain injury. *Journal of the International Neuropsychological Society*, 14, 289-296.
- Ylvisaker, M., Turkstra, L., Coelho, C., Yorkston, K., Kennedy, M., Sohlberg, M., & Avery, J. (2007). Behavioural interventions for children and adults with behaviour disorders after TBI: A systematic review of the evidence. *Brain Injury*, 21(8), 769-805.